



**TEENAGE  
CANCER  
TRUST**

**WE'RE HERE**

**FOR YOU**

**Services for young people  
with cancer at UCLH**

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A vibrant forest scene with a carpet of purple flowers and tall, thin trees. Large, white, bold text is overlaid on the right side of the image. On the left, there are three white rectangular shapes: a long horizontal one at the top, a square one in the middle, and another square one below it.

**TEENAGE**

**CANCER**

**TRUST**

# **WE'RE HERE** **FOR YOU**

**First of all, we want you to know that we're on your side. Starting right now – for as long as we're looking after you.**

Most people have a thousand questions. What happens next after a cancer diagnosis? How can I get the help I need? What do all the confusing NHS abbreviations mean?

Everyone in the Teenage and Young Adult Cancer Service here has loads of experience in helping people your age. So they understand all the special challenges that having cancer in your teens or early twenties can bring.

Later in this booklet, we'll introduce you to the different services and teams here at University College London Hospital (UCLH) and explain how you can get their help.

As well as giving you the best medical care we can, we're also here to help you with practical stuff. And to lend you a friendly ear and a shoulder to lean on. And if there's anything you need that's not mentioned in this booklet, please ask one of us and we'll see what we can do.

# **IF YOU DON'T UNDERSTAND PLEASE TELL US**

**It's really important to us that you understand what's happening with your treatment.**

- Your team should make it clear where you'll receive your care, who'll look after you and what tests, treatment and support you can expect. This is sometimes called your 'care pathway'.
- You should be offered the right tests and the best treatment for your particular type of cancer. All of your care should be safe and take your age into account. And if there's a clinical trial that could help you, you should be offered the chance to take part.
- Your care should always be well-planned and smoothly coordinated. All the professionals involved should keep each other informed, avoid giving you mixed messages, and let you know about any changes.
- You should always be given the right information and support to make choices about your care and to help you understand what's happening to you. Everyone on your team should listen to you and take your views into account.

So if ever you're not sure of something, please just ask a member of the team. We'll talk you through it until everything's clear.

## **KEEPING YOUR INFORMATION CONFIDENTIAL**

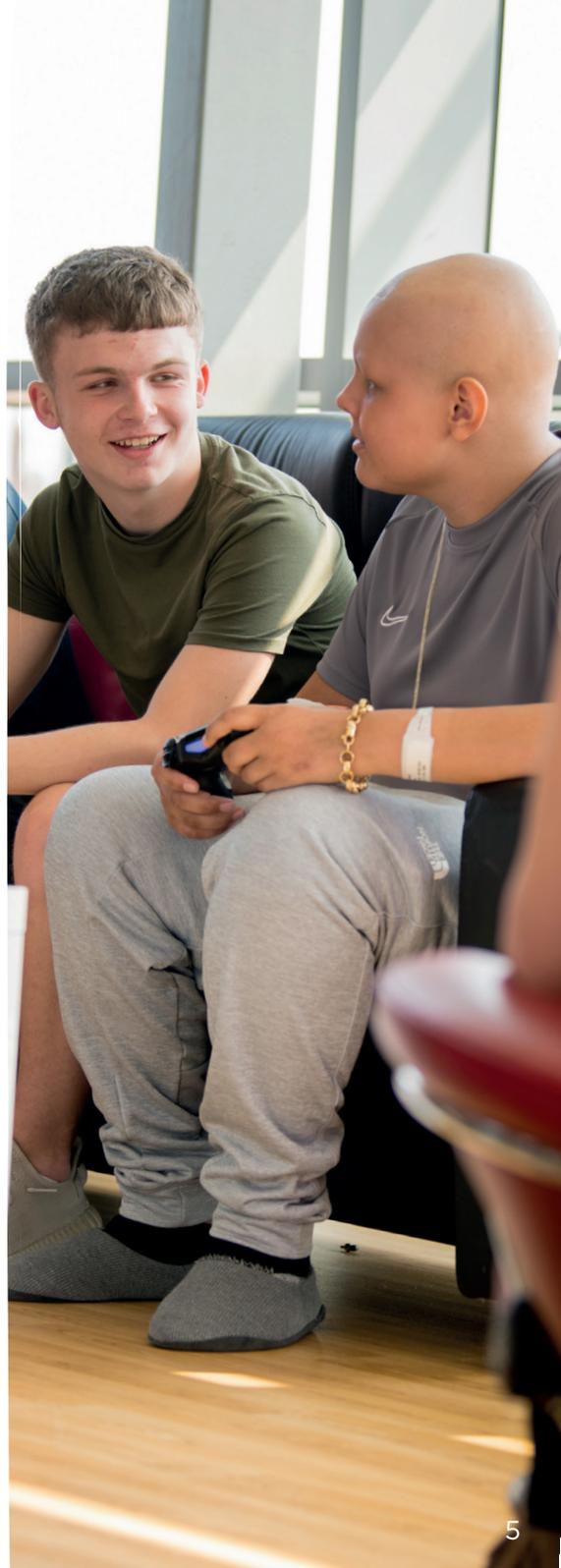
Everyone involved in your care has a legal duty to keep your information private. Rest assured that they'll only share it with other professionals if it's necessary for your care.

## **WHY YOU'VE BEEN REFERRED TO UCLH**

**University College London Hospital is one of the UK hospitals which specialises in cancer care for people your age.**

We cover North London, Essex and some parts of Buckinghamshire and Hertfordshire. We work with other hospitals in these areas to provide some care closer to home where possible. Your clinical team will explain this in more detail.

We're also a specialist centre for sarcoma, proton beam therapy, radiotherapy and CAR-T cell therapy, so we receive some referrals from further away.



# WHERE DO WE FIT INTO YOUR CARE?

**Your treatment plan has been created by a team of doctors and other healthcare professionals who are experts in your specific cancer, to make sure you get the best possible care.**

Our role in the Teenage and Young Adult Cancer team is to work closely with your doctors to support you and your family. We're here to help with any emotional, practical, physical and educational needs you may have, during your treatment and afterwards.

Our team come from different professional backgrounds and even different organisations but we're all specialists in caring for young people with cancer. On these pages you can read a bit more about the different people you might meet.

## WHO'S PART OF YOUR TEAM?

*Here's a handy guide to everyone...*

### **Doctors**

Our experts in different sorts of cancer make sure you get the right treatment for you, including any suitable clinical trials.

### **Nurse Consultant**

They will offer support to you and your family wherever you decide to have your treatment.

### **Nurses**

Our friendly nursing team will take care of you while you're here. They'll all work closely with your wider medical team to make sure you get the best possible care.

### **Clinical Nurse Specialist (Key Worker)**

Your Clinical Nurse Specialist (also called your Key Worker or CNS) is a nurse with cancer expertise who co-ordinates your care. So if you're worried and need advice or support, you know who to call.

### **Young Lives vs Cancer Social Workers**

They offer emotional, financial and practical support so you can carry on with as much of your normal life as possible during treatment and recovery.

Find out about their services at  
**[younglivesvscancer.org.uk](http://younglivesvscancer.org.uk)**



### **Youth Support Coordinators**

Your Youth Support Coordinator (YSC) organises events and activities that bring young people together on your unit. Young people often say being with others who understand what they're going through can be a valuable source of support. If you're worried about your treatment or a procedure, your YSC will help you make choices and feel more in control.

### **Teachers / Educational Support**

Our teachers are here to help you stay on top of your studies. They'll keep in touch with your school or college and coordinate work with your teachers. And if you need to sit an exam in hospital, they can help with that too.

### **Psych-oncology Team**

This team specialises in supporting you, your family and your partner (if you have one) with the psychological effects of cancer. It can really help to have some space for yourself, as a family or in a group to make sense of what's happening.

### **Physiotherapy Team**

Your physiotherapist can design an individual programme for you to help keep your independence and ability to do normal physical activities as far as possible.

### **Pharmacists**

Our pharmacists are on hand every day to help prescribe any medicines you need and answer your questions.

### **Occupational Therapists**

During or after treatment, our therapists will work with you to help you keep your independence. They can also help with returning to education or work, relaxation, dealing with fatigue and more.

### **Nutritional Support / Dietitian**

If you're worried about maintaining a healthy diet, your dietitian can assess your needs and offer advice.

### **Complementary Therapists**

Therapies like massage, aromatherapy, reflexology and reiki can help with treatment side effects, and promote better relaxation and more energy. Carers can have treatments too. And music therapy is also available. Just ask your Clinical Nurse Specialist for more information.

### **Advanced Nurse Practitioners (ANPs)**

ANPs work alongside medical and CNS teams to offer consistency of care for young people, and expert knowledge of cancer and its effects.

# WHAT CAN YOU EXPECT?

## OUR INPATIENT WARD FOR 13-19 YEAR OLDS

### WHERE YOU'LL GET YOUR CARE

#### 13 to 18 years old

Most of your treatment will be at UCLH but some care might be at your local hospital.

#### 19 to 24 years old

You can choose between treatment at UCLH or your local hospital.

Wherever you choose to be treated, our Teenage and Young Adult team will regularly discuss and get involved in your care and your treatment plan.

Our 20-bed teenage ward (known as T12N) was designed with and supported by Teenage Cancer Trust. It has everything you need to make your hospital stay as comfortable as possible including:

- A plasma TV in every room
- Wi-fi access
- A webcam to stay in touch with friends and family
- A social area to hang out with others
- A kitchen for drinks and heating up meals
- An extra bed so someone close can stay with you
- Two Youth Support Coordinators on hand

## OUR INPATIENT SERVICES FOR 20-24 YEAR OLDS

If you're aged 20-24 and being treated for a blood cancer, you'll normally stay on Level 3, Grafton Way Building. If you're aged 20-24 and being treated for a solid tumour, you may be admitted to Ward T13.



## Services on the wards include:

- A social area
- Wi-fi access
- Entertainment unit – either built-in or mobile
- A designated Lead Nurse who specialises in care for teenagers and young adults
- A designated Youth Support Coordinator

If you have extra needs, or there aren't any free beds on those units, you might stay on one of the other cancer inpatient wards at UCLH. Whichever ward you're on, your care will always be supervised by the Teenage and Young Adult Cancer team – don't worry, we'll know where you are!

If you want any activities or facilities that aren't available on the ward you're on, just ask and we'll see what we can do.

**AMBULATORY CARE** is when you're having ongoing care from us but you don't need to stay in a hospital bed overnight. A good example is when your chemo drugs are pumped from a special rucksack that you wear so you're free to walk around and go out. In this case you can stay in accommodation nearby and come into the hospital every day for a review.

## DAYCARE, OUTPATIENTS AND AMBULATORY CARE

Our outpatient and daycare services are delivered on the 3<sup>rd</sup> floor of the UCLH Macmillan Cancer Centre where you'll also have access to:

- Drink-making facilities
- A gym
- A gaming area
- Computer areas
- Arts and crafts facilities
- A designated Youth Support Coordinator

## PHOTON AND PROTON BEAM RADIOTHERAPY

As one of only two proton beam therapy services in the country, and a large provider of photon beam therapy, UCLH receives a large number of young people from across the South of England for radiotherapy treatment.

If you're also having chemotherapy, you can receive this on the ward or in daycare as needed. Both services are covered by a Youth Support Coordinator, and there's a social space for teenagers and young adults in the basement of the proton beam therapy centre.

## **FAMILY ACCOMMODATION**

If you and your family need somewhere welcoming and friendly to stay close to the hospital, Paul's House is a home-from home provided by Young Lives vs Cancer:

**[younglivesvscancer.org.uk/  
pauls-house-london](http://younglivesvscancer.org.uk/pauls-house-london)**

If you are well enough, you might also be able to stay at Paul's House for part of your treatment. Just ask us if you're interested.

If you're receiving ambulatory care, accommodation is also available in the Cotton Rooms, a free, four-star boutique hotel specially for people getting treatment at UCLH. Most guests there are receiving cancer treatment.

**[cottonrooms.com](http://cottonrooms.com)**

## **WILL YOU MEET OTHER YOUNG PEOPLE WITH CANCER?**

Yes. UCLH is a Specialist Treatment Centre for teenagers and young adults with cancer and many of the people we treat find it really helps to support each other and share experiences. With that in mind, our team of Youth Support Coordinators arrange events and activities where you and your family can meet others who are going through the same thing. Some of the charities listed opposite organise local events too.

## **HANDING OVER YOUR CARE AS YOU GET OLDER**

### **Aged 13-19**

Your care is managed by the Teenage and Young Adult Cancer Service at UCLH. This will include a haematology (blood) or oncology (cancer) medical team and a Clinical Nurse Specialist. Around your 20<sup>th</sup> birthday, your care will be handed over to the relevant team in the adult cancer service.

### **Aged 20-24**

After your care is handed over to the adult service, you'll be treated on one of the adult wards if you need inpatient care.

Any daycare, outpatient and ambulatory care you need will continue on the 3<sup>rd</sup> floor of the UCLH Macmillan Cancer Centre until your 25<sup>th</sup> birthday.

Other members of our team – like the Youth Support Coordinator, Social Worker and Psych-oncology team – are available until your 25th birthday.

### **Aged 25 and over**

After your 25<sup>th</sup> birthday, you'll be looked after at the adult day care and ambulatory care service on the second floor of the Macmillan Cancer Centre.

The Teenage and Young Adult team will show you the facilities and introduce you to the team there before you move.

# USEFUL CHARITIES

These charities all offer a range of services and support that you might find helpful. We've included a short description for each of them but it's worth visiting their websites for full details.

## **CANCER RESEARCH UK**

**[cancerresearchuk.org](http://cancerresearchuk.org)**

Research, awareness and information.

## **CHILDREN'S CANCER AND LEUKAEMIA GROUP**

**[cclg.org.uk](http://cclg.org.uk)**

Information for families affected by childhood cancer.

## **YOUNG LIVES VS CANCER**

**[younglivesvscancer.org.uk](http://younglivesvscancer.org.uk)**

Support, information and guidance for young people and families, including grants and financial advice.

## **MACMILLAN CANCER SUPPORT**

**[macmillan.org.uk](http://macmillan.org.uk)**

Support, information and advice, including grants and financial advice.

## **SHINE CANCER SUPPORT**

**[shinecancersupport.org](http://shinecancersupport.org)**

Meet-ups, information and advice for those in their 20s, 30s and 40s.

## **TEENAGE CANCER TRUST**

**[teenagecancertrust.org](http://teenagecancertrust.org)**

Specialist care and support for anyone diagnosed with cancer aged 13-24.

## **TEENS UNITE**

**[teensunite.org](http://teensunite.org)**

Workshops, activity days and residential stays.

## **TREKSTOCK**

**[trekstock.com](http://trekstock.com)**

Supporting young adults through cancer treatment – and beyond.

## **WILLOW FOUNDATION**

**[willowfoundation.org.uk](http://willowfoundation.org.uk)**

Offering uplifting and unforgettable Special Days to seriously ill young adults aged 16 to 40.

# GETTING IN TOUCH WITH US

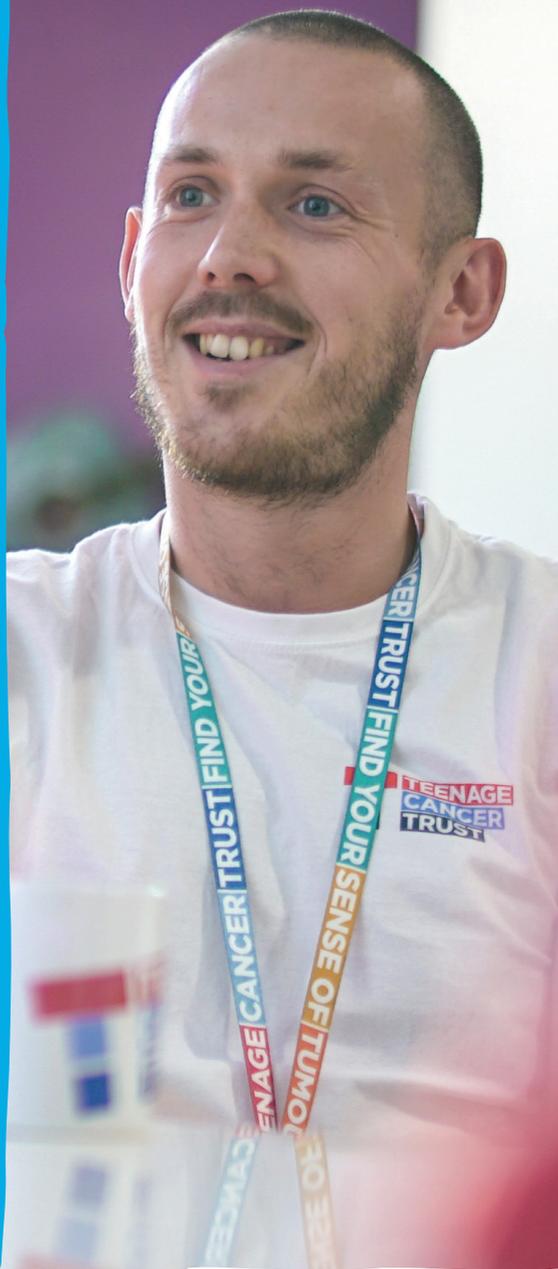
**Everyone who uses this service will be allocated a Pathway Coordinator. You should contact your Pathway Coordinator if you want to meet or talk to any of your clinical team.**

Here are their numbers  
(Mon-Fri, 9am-5pm):

**Oncology Pathway  
Coordinator:  
07534 324 703**

**Haematology Pathway  
Coordinator:  
07534 324 591**

Your Clinical Nurse Specialist will give you out-of-hours contact details if you need any help or advice in the evening or at the weekend.



[teenagecancertrust.org](https://teenagecancertrust.org)



Teenage Cancer Trust is a registered charity: 1062559 (England & Wales), SC039757 (Scotland)